Testimony of Valerie Harper U.S. Senate Special Committee on Aging May 7, 2014

Good afternoon. My name is Valerie Harper and I'm very pleased to be joined by my husband Tony Cacciotti. We're both honored to be here.

I am a lung cancer survivor.

Chairman Nelson, Ranking Member Collins and other distinguished members of the Committee, thank you for inviting me to share my story today and to discuss a topic about which I have become quite passionate: funding for cancer research, particularly lung cancer.

Five years ago, March 2009, I needed surgery on my left wrist to repair an injury. I underwent the required pre-surgery chest x-ray, which shockingly revealed something was in the top lobe of my right lung that shouldn't be there. The wrist surgery was immediately put on hold, and the spot in my lung was diagnosed as a Stage 2 cancerous.

Thankfully, my surgeon at Cedars Sinai, Dr. Robert McKenna, in 1992, had pioneered a truly brilliant lung surgery procedure, Video Assisted Thoracoscopic Surgery, or VATS. It's like arthroscopic knee surgery – but for the lung. There was less bleeding, a much quicker recovery. And tiny scars because it's minimally invasive.

Every 6 months since that surgery in 2009, my lungs were scanned for any sign of recurrence. My lungs have been free of lung cancer – I was surgically cured of lung cancer! For 4 years.

But then in January 2013, there it was again, in a new form – Leptomeningeal Carcinomatosis, known as lepto, a rare and incurable cancer that occurs in the membrane that surrounds the brain. It took over a month of testing to conclude that my lung cancer had returned – not to my lung but to the lining of my brain.

Cancer reminds me of a very bad but tenacious performer, who although no one wants to see, insists on doing an encore, having a return engagement, making a comeback and worst of all, going on tour. In my case, so far, it seems to be held at bay under the watchful eyes of my oncology team, Dr. Ronald Natale and Dr. Jeremy Rudnik. I take my prescribed medications religiously, have regular brain scans and whole body testing twice a year to see if the cancer has moved. I also take TCM (traditional Chinese medicine) tea, have acupuncture and engage in visualization ridding myself of cancer.

Questions I have asked myself include why did I get lung cancer? And what would have happened to me if it wasn't discovered accidentally? But let's talk about the facts for a moment first:

- 1. Lung cancer is the #1 cancer killer in the United States among both women and men.
- 2. More than two-thirds of all lung cancers occur among never or former smokers, although the majority are among former smokers.
- 3. Lung cancer can also be caused by being exposed to secondhand smoke, air pollution and radon. Radon is a colorless, tasteless and odorless gas that causes lung cancer.
- 4. Genetics also play a role in developing lung cancer.

While I never smoked, I was exposed to secondhand smoke for decades. My mother also developed lung cancer, died of it. She too never smoked. So I had two risk factors – secondhand smoke exposure and possibly my genetics.

But that still begs the question. Why must most lung cancers be found by accident as opposed to having a reliable method for early detection? While I am grateful the x-ray revealed the cancer, it highlights a troubling fact in lung cancer: seventy-five percent of all lung cancers are found too late – at later stages once the disease has already spread. As a nation, we must prioritize health funding and funding for research and that starts here in the Congress.

In my capacity as a lung cancer survivor, I've gotten involved with the American Lung Association. They advocate for increased federal funding for the National Institutes of Health, including the National Cancer Institute. And while I won't pretend to understand the federal budget, I do know "research dollars equal lives."

There have been many recent exciting advancements in fighting lung cancer over the last few years. Tumors can now be tested for genetic markers that can lead to personalized treatments like I'm receiving. Landmark research conducted by the National Cancer Institute in the last decade has led to the U.S. Preventive Services Task Force awarding a "B" grade for screening people for lung cancer if they meet the definition of "high risk." Starting January 1, many people at high risk who have private insurance will be eligible for screening at no cost. Medicare is currently in the midst of a process to determine whether they will cover this screening for high risk individuals as well. But this is only a first step.

Research is desperately needed for early detection of the disease in people who aren't at high risk for developing lung cancer – people like me. Thank god I broke my wrist and needed surgery. Luck is not an acceptable substitute for early detection.

Research on new treatment options are also needed for when lung cancer is detected in stages 3 and 4. Chemo remains the first line treatment for many lung cancer patients, despite its difficult side effects. For 20 percent of lung cancer patients with a known genetic marker,

personalized treatments are available which are less toxic and more effective against specific tumors but more work is needed on biomarkers and targeted therapies.

But how can these investments in lifesaving research occur when all we hear from Washington is about cutting spending? We must stop thinking of spending and start thinking of investments. Meaningful increases in federal research investments are desperately needed to improve early detection and treatment options.

Last week, the head of the National Institutes of Health, Dr. Francis Collins, appeared before the Senate Committee on Appropriations and said – and I quote – "The worst thing you can do for biomedical research is this 'feast or famine,' where you rev up the engine or you take away the fuel." This of course applies to lung cancer research as well. Sustained investments in funding for cancer research will win our race against lung cancer.

Thank you again for the opportunity to speak with you today.